



## **SIPD UGANDA REPORT ON THE FIRST REGIONAL CONSULTATIVE MEETING ON INTERSEX (SEX DEVELOPMENT DISORDERS) HEALTH AND RIGHTS – KAMPALA, APRIL 2013.**

### **SUMMARY**

*On the 22/04/2013, the Support Initiative for People with congenital Disorders (SIPD) organized the first ever regional consultative meeting on sex development disparities – also known as intersex conditions – in Kampala, Uganda. The meeting brought together participants from all five East African countries in East Africa. This report narrates the conversations, outcomes, and recommendations from the meeting.*

### **1.0 BACKGROUND**

The aim of the regional consultative meeting was to provide a pioneer space for regional conversations and comprehensive consultation on intersex health and rights in the East African region. SIPD sought to bring together 20 key healthcare providers, legal practitioners, civil society leaders, government and community representatives, intersex people, parents of intersex children, and human rights activists to engage on how they can provide safe spaces for intersex children and people, as well as parents of intersex children in their respective fields.

The meeting had the following five key aims:

- Facilitate knowledge transfer, technical support, and amplified advocacy voices around health and rights for intersex children and people in East Africa.
- Initiate the creation of a critical mass of intersex allies and stakeholders who are confident in their methodologies and theories in addressing issues surrounding the right to health, choice, life, and dignity for intersex children and people in the region; and who appreciate and target the role

that class, ethnicity, culture, education, and religion play in fuelling marginalization for this population.

- Upscale the support and advocacy networks for intersex health and rights in East Africa
- Document and disseminate best practices in Intersex interventions with a regional focus.
- Increase the profile of grassroots national responses to Intersex issues of concern in an East African regional space.

### **1.1 THE MEETING**

The meeting started with the introductions of all present members, we had representatives from Kenya (GMAT F) in Kenya, Human Development Initiative (HDI) in Rwanda, ABUBEF in Burundi (ABUBEF), FOCUS Tanzania, Centre for Domestic Violence Prevention (CEDOVIP) and a media representative, Human Rights Awareness and Promotion Forum (HRAPF), Refugee Law Project (RLP), Reproductive Health Uganda (RHU), STRAIGHT TALK, RAISING VOICES, Uganda Health and Press Association (UHSPA), MARPI and the School of Public Health from Mulago hospital in Uganda, four(4) intersex youth, and three (2) parents of intersex children.

The Executive Director of SIPD-Uganda welcomed the participants and gave a background to the meeting. His prelude included clarifying definitions – “intersex” versus ‘hermaphrodite”. He further explained why SIPD had chosen the particular participants present for this pioneer regional meeting and what expectations SIPD and the intersex clients in the entire region have of the institutions represented at the meeting. In his opening remarks, he

explained intersex as an ambiguity in sex development. This is normally at the genital level and can be seen at birth however, for some people it may show much later in life as one grows as it is at the chromosome or hormonal level. Intersexuality is a minority issue which was and still is not recognized as such by most people in our regions, but most children who are born intersex are killed, their parents especially the mothers are subjected to domestic violence by the husbands and in-laws. With increased community outreach however, many parents, particularly mothers are starting to speak out and to seek safe spaces where they can ‘grow’ safe solutions to the health and social needs of their children as well as their own without losing a livelihood.

Therefore, SIPD, with the support of its development partners decided to break the silence by addressing this with the parents and other community custodians, lawyers, reproductive health practitioners, counselors, government (esp., the Ministry of health, Ministry of education, Ministry of gender, labor and social development, the Uganda Human Rights Commission) and the police to see that the intersex people are recognized, and their health and rights acknowledged. The biggest problem we are facing is the lack of psychosocial support and actual health services to the clients. Intersex is a new subject in terms of programming which therefore needs to be prioritized, the most affected people are the mothers yet they are the most secretive hence making it hard to assist these children who are entirely in their hands. There is need to share experiences and get solutions to this pressing issue, need to build a critical voice to address this because many milestones are not addressed to the expecting mothers, the children in schools who are also affected, the teachers and caretakers of these children and many mutilations that are based on best guess surgery have turned out sour, and many difficulties are faced at a later stage when, for example, it is necessary for someone to change their names or sex. Our aim in convening this regional consultative meeting was to find ways in which we can upscale our networking and alliance building across borders and create more safe spaces closer to the intersex East Africans who badly need these spaces.

### **1.1 EXPECTATIONS FROM PARTICIPANTS**

- ✓ Discussions of the relationship between the intersex people and their parents (Do they face any form of rejection)

- ✓ Discussing differences around sexuality and sexual orientations as opposed to sex development
- ✓ How much knowledge do people have about intersexuality and policy matters
- ✓ Apply the learnt knowledge back home in their own regions
- ✓ Expect to get a clear understanding of intersexuality to the rest of the region
- ✓ How to present intersexuality so that it is not looked at as homosexuality
- ✓ Looking at ways which intersex can be disengaged from the LGBT family
- ✓ Expect to get clarity from doctors about what exactly happens to bring about this disorder
- ✓ Having a national policy, a registry and a clinic that follows up on these issues
- ✓ Learn about the issues affecting intersex children
- ✓ Broaden or include intersexuality into pediatric system/clinic and then child health care

### ***1.2 The meeting examined the pros and cons of including the I (Intersex) in LGBTI community in regard to organizing***

Deliberations revealed that “intersex” as a collection of anatomical conditions, was shrouded in silence and even though the founder of intersex rights organizing in the region found some engagement spaces within the LGBT community, it was important to note that this lack of autonomous attention has made intersex children and people just another letter within LGBTI organizing but has not achieved the space that was anticipated to cater to the needs of this constituency. One of the thoughts from the meeting was the need to find ways to engage on intersex issues separately from – albeit in ally ship with partners from – the wider LGBT and other minority groups ones such as people with disabilities, children at risk, and survivors of torture etc. and be able to articulate the urgent gaps and needs that must be addressed. Intersex people lived in denial and found it really hard to come out and say that they are intersex and therefore the best they could do was to hide under the umbrella of the LGBT family seeking acceptance and recognition.

The other reason identified was the need to access funds to be able to organize since almost all funders available at the time had LGBT constituencies as their only target of interest.

### ***1.3 The meeting identified the following rights of the child that activism and organizing around sex development irregularities targets to address:***

- ✓ Right to life
- ✓ Right to education (most children drop out of schools once they feel that they are not as normal as the other children in school and this is shouldn't be the case)
- ✓ Should have a sense of belonging
- ✓ Should not be discriminated against and neither should they be stigmatized
- ✓ Right to informed choices regarding surgical body modifications
- ✓ Most children are raped out of curiosity about their behavior in the environment
- ✓ Others are used in witchcraft and some are even sacrificed

### ***Rights of the adult with sex development irregularities***

- ✓ Right to appropriate healthcare and information
- ✓ Right to a socially and economically productive life
- ✓ Right to found a family, regardless of whether the individual can or cannot “consummate” a union in the traditional sense.
- ✓ Right to access legal support in changing best guess sex assignments at birth whenever the individual is able
- ✓ Right to appropriate sexual and reproductive health services and information, including appropriate support for resultant disabilities.
- ✓ Right to safe social spaces to share experiences, build community, and draw support

## **2.0 PRESENTATIONS**

### **2.1 PRESENTATION BY DOCTOR KIGGUNDU**

#### ***2.1.1 Health/Medical explanation of intersexuality***

Dr. Kiggundu from Mulago hospital took participants through a scientific and clinical journey of how intersexuality occurs and what kind of medical and health issues are typically bound to occur, and how fathers are and should be considered a key part in determining the intersex child's anatomy. The biological explanation being that only males give off the Y chromosome, which is the sex determinant and has a sex determination gene; and in the absence of which, there is likely to be a disorder in sex development.

**Lessons and recommendations from the presentation:** Most disorders are not life threatening because they don't normally affect the enzymes necessary for growth. It is only those that affect the enzymes that are dangerous and children may not live for more than 72 hours. However, he recommends continued follow up of children and families for at least ten years before any surgical conversations are held.

Children should be in position to decide what sex they should be according to how they feel at a later stage in life and not have their bodies mutilated without their consent which may yield sour results later on in life and yet it is irreversible at the time. Only when it is critical and advised by a doctor should it be done at to save the life of the child. The various medical treatments available in Kenya, which is part of the region, include cosmetic surgeries, hormone replacement treatment, chromosomal and other cytogenetic tests and in Uganda, only hormonal and imaging tests can be accessed.

He also addressed some of the following participants concerns:

- ✓ ***Can one be intersex and not know?***
- ✓ ***Is intersex a subset of Hermaphrodites?***
- ✓ ***Does the clitoris erect to resemble a small penis in an intersex case?***
- ✓ ***At what stages beyond infancy is one likely to detect these sex development disorders?***
- ✓ ***Does it have a direct bearing on gender inclination***

### **2.2 PRESENTATION BY DIANA –CEDOVIP**

#### ***2.2.1 Intersexuality and Domestic Violence***

Ms. Diana led the participants in a discussion that defined violence, i.e. as any action or inaction that may cause or endanger someone's life and how violence is bound to be a daily reality for intersex children, mother of these children and intersex people in schools and in the workplace. Much of this violence takes the form of psychological and physical abuse. Examples from the conversations included the following:

- ✓ Ridicule
- ✓ Fear
- ✓ Verbal abuse
- ✓ Economic abuse
- ✓ Physical abuse (Kicks, slaps)
- ✓ Discrimination and isolation
- ✓ Lack of confidence by parents
- ✓ Rejection and neglect of child by parents, of mother by father and in-laws
- ✓ Sexual abuse (curiosity and blackmail rape)

Note: Some domestic violence is as a result of infertility in a home (and is always assumed to be the woman's problem) which in most cases may be caused by disorders of sex development and the victim may not even be aware of this.

### **2.2.1 Recommended interventions**

- ✓ Relocation especially to deal with depression and suicidal tendencies
- ✓ Wholesome counseling which should be done regularly
- ✓ Parents must have confidence in their children and love them above anything else
- ✓ Policy advocacy at the national and regional legislative levels
- ✓ Revision of the science syllabus especially in primary schools and in medical schools
- ✓ Create safe spaces/homes for the intersex children and people
- ✓ Service providers should provide services to all and not discriminate against the intersex
- ✓ More sensitization and understanding of the term intersex to eliminate the initial term-hermaphrodite and probably adopt the use

of a more health and reproductive term so that Intersex is not continually hidden and looked at through the lens of homosexuality

- ✓ The "I" should be excluded from the LGBTI family in terms of organizing and autonomously address its issues.
- ✓ Create a comfortable space for people to come out and speak
- ✓ The CSO should get direct representatives from the Intersex community

## **2.3 PRESENTATION BY HRAPF (FRIDAH)**

### **2.3.1 Intersexuality and Rights**

HRAPF provides free legal aid services to everyone including the LGBTI community. She explained to participants the current limitations within Ugandan laws. For example, the Ugandan law books don't define intersex and everyone at birth is regarded as children, there is no differentiation and these children have rights such as;

- ✓ Right to stay with their parents
- ✓ Right to education
- ✓ Protection from discrimination
- ✓ Right to proper nutrition
- ✓ Right to proper and adequate health

Therefore, intersex children should have equal right opportunities as every other child in the country. The law provides for change of sex and change of name however it should all be done before one turns 21 years of age.

The law is further abused by parents and doctors who do corrective surgery when the children are still young and cannot decide for themselves but at times we don't blame them because doesn't let them decide after they make 21 years hence we should join together to pass and oppose this law.

## **3.0 REGIONAL EXPERIENCES**

### **3.1 KENYA**

There was an intersex who was fed up of being in hiding and wanted to be legally recognized which he did but this led to so much friction in the country

as the stand continued to be that God had only created man and woman and no one else in between therefore there was no such thing as Intersex. His rights were so much violated that he didn't even go to school, didn't have a birth certificate therefore he had no identification at all and this made life very difficult for him as he felt left out and rejected.

Accept the intersex and they will come out to address this issue and seek medical assistance as well and then also there should be provision of a 3<sup>rd</sup> gender that caters for those born intersex.

### **3.2 RWANDA**

Rwanda is very silent on the issue of intersex and as a matter of fact it is almost unheard of and there is completely no organization that is dealing with this meaning that the intersex people who are there are suffering silently. The CSO is creating a health and rights segment which will be advocating for the intersex and then there will be training of lawyers, TBAs, Doctors, and parents about intersex. Rwanda reps requested for continued collaboration, especially in terms of sharing educational information and materials, which they can customize and translate to their own languages to start engaging on this issue.

### **3.3 BURUNDI**

Health services are provided by other organizations but ABUBEF is a member of IPPF and there is no data base about intersex people and children in general although they know that these cases exist. The only current interventions and standard treatments include silence and at best when hospitals or healthy centers receive an intersex person, the only thing that could be provided corrective surgery, most of which is not preceded by any lab or imaging tests whatsoever.

Many associations have not prioritized intersex health and rights mainly due to the social silence around it and partly due to misunderstanding it to be a sub –set of homosexuality, such that people with infertility and other sexual development issues would rather identify themselves with disability interventions. This has pushed this conversation to the back of public

dialogue even though there are several initiatives to promote health and rights in Burundi. Therefore, no specific documentation of cases has been done

### **3.4 TANZANIA**

The message received from FOCUS Tanzania is that they have been privately attending to parents who report intersex traits in their children but have only provided counseling due to lack of other facilities or knowledge. After initial visits, the parents would not return to the hospital but rather seek the services of traditional medicine men and women. No documentation of cases has been done.

### **3.5 UGANDA**

We screened “MY SECRET LIFE” a SIPD documentary of Ugandan intersex lived realities and stories by intersex people, medical practitioners, parents, and community workers. The documentary had a clear message on what the critical needs and issues for intersex people in Uganda are, as well as recommendations on what interventions they would like to have available.

## **4.0 RECOMMENDATIONS**

- ✓ There should be more sensitization of stakeholders and health practitioners
- ✓ Sensitize the local government and ministries
- ✓ Documentation and follow up at all hospitals and the TBAs should also do some kind of documentation
- ✓ Awareness creation and inclusion of the ministry of Education, ministry of gender, labor and social development
- ✓ Media inclusion, production of more IEC materials, doctors should also engage in parent education and awareness that there is a possibility of having a child who may neither be male or female
- ✓ Advocacy should be taken at a higher level for example law makers, parliamentarians,
- ✓ Involve other open minded organizations that are ready to work with us
- ✓ Get key messages to publish and these should be repackaged. The use of the term “intersex” poses interpretation challenges and diverts the

issues we are trying to address to a homosexuality conversation. It was recommended that since there are many other spaces where same sex rights are addressed, the health and rights issues of children and people with sex development disparities should be de-linked to give this constituency a chance to access appropriate support systems.

- ✓ Be clear on our referrals for instance; know where to go for surgeries, psychosocial support, tests and so on
- ✓ Identify potential partners and allies for advocacy
- ✓ Improve our referral system and share this information with participants
- ✓ Share the policy concept note submitted to the Ministry of Health and the Uganda Human Rights Commission with participants so they can identify how to contribute their voices and experiences to the cause.
- ✓ Need for our own clinic to attend to this just like other issues have their own like TASO for HIV, the cancer institute, Pediatric clinic, and Most at Risk Populations, Mental Health victims etc. in order to accurately document and customize health information and services.
- ✓ Initiate a regional coalition working to promote to sexual and reproductive health and rights of intersex children and people.

## **6.0 POTENTIAL PARTNERS AND ACTION PLANS SUGGESTED BY PARTICIPANTS**

- ✓ National council for children
- ✓ Action AID
- ✓ Teenage centers
- ✓ Family protection unit of the police
- ✓ Advertisement houses – bill board regulators
- ✓ Initiate a Facebook page and a regional list serve to continue sharing information and referrals
- ✓ Donors and embassies\*
- ✓ Write something about Intersex on important days for instance the World Population Day, Day of the African Child, etc
- ✓ Referral directory\*
- ✓ SIPD should do a more comprehensive situational analysis in Uganda to back up the pilot policy reform advocacy actions that have been started.

## **7.0 OTHER RECOMMENDATIONS AND OBSERVATIONS FROM PARTICIPANT EVALUATIONS**

- ✓ A louder voice and breakage from LGBT is needed- (Uganda) It has given a green light to other regions (countries) and some kind of commitment to start considering intersex critically- (Rwanda)
- ✓ Share documentation on intersex- (Burundi, Tanzania)
- ✓ We should have a dedicated clinic for practical research - (Uganda, Kenya, Burundi)
- ✓ Repackage the messages and terminologies that we have to replace “intersex” with a more plain description of the actual sex development issue being addressed - (Uganda)
- ✓ Special focus should be put on the feasibility of marriage between the “I” and the wider “LGBT”organizing.-(Uganda)
- ✓ If messages could also be put in local languages-(Uganda, Kenya, Burundi, Tanzania)
- ✓ More research should be made around the subject-(All participants).
- ✓ Was a very crucial meeting and they are ready to render any kind of assistance to SIPD anytime they are approached-(Uganda)

## **8.0 CONCLUSION**

The meeting came to a conclusion after the evaluations were done and generally it was a success as we managed to achieve the set goals for this meeting, which were, coming together as a collective regional voice to consult on how best we can achieve effective organizing for the health and rights of intersex children and people in the East African region and how to amplify these issues and place them on public discourse agendas in the region. The 1 pager communique being formulated is a working document that highlights the need, the objective of the meeting, the countries represented and the recommendations that these representatives put forward as next steps.

## **APPENDIX 1**

### **ACRONYMS**

**GMAT F**-Gender Minority Advocacy Trust Fund (Kenya)

**ABUBEFU**- Association Burundaise Pour Lebien etre Familial (Burundi)

**MARPI**-Most At Risk Population Initiative

**IDI**-Infectious Disease Institute

**RLP**-Refugee Law Project

**CEDOVIP**-Centre for Domestic Violence Prevention

**HRAPF**-Human Rights and Awareness Promotion Forum

**HDI**-Health Development Initiative (Rwanda)

**RHU** – Reproductive Health Uganda

**IPPF** – International Planned Parenthood Federation

**LGBTI** – Lesbian, Gay, Bisexual, Transgender, Intersex

### **A cross section of photos from the meeting**

